Select Special Health Information Act Review Committee

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Consultation Guide

Legislative Assembly of Alberta

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The Select Special Health Information Act Review Committee

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Introduction

Alberta's *Health Information Act* (HIA) became law on April 25, 2001. This legislation protects the privacy of Albertans and the confidentiality of their health information. It balances the protection of privacy and confidentiality with the need to enable health information to be shared and accessed where appropriate, to provide health services and to manage the health system.

This legislation provides individuals with the right to access their own information and to have that information protected from inappropriate collection, use and disclosure.

The legislation requires that a Special Committee of the Legislative Assembly begin a comprehensive review of this Act within 3 years after coming into force.

Alberta is one of three provinces that has enacted sector specific health information legislation recognizing the unique characteristics of personal health information. Manitoba proclaimed the *Personal Information Act* in 1997, Alberta proclaimed the HIA in 2001 and Saskatchewan's *Health Information Protection Act* came into force on September 1, 2003. Ontario's *Health Information Protection Act* received Royal Assent in the Spring, 2004.

The rules in the HIA are based on a set of internationally accepted fair information principles. In general terms, the Act extends to Albertans two basic rights. The first is the right to privacy and confidentiality of the individual's health information. The second is the right to access their own information in the custody or under the control of custodians including the right to examine, obtain a copy of, or request a correction or amendment to recorded personal health information.

This document has been prepared as part of the review process and is intended to focus the review on key issues. These are by no means the only issues the Select Committee of the Legislative Assembly is willing to consider. Your feedback on any of the issues regarding collection, use and disclosure and protection of personal health information is required and appreciated.

The rights of Albertans are reflected in the provisions of the HIA and the duties and obligations placed on custodians to protect information from unauthorized collection, use and disclosure. The Act provides for independent reviews of decisions made by custodians under the Act by Alberta's Office of the Information and Privacy Commissioner.

Background

The *Health Information Act* came into force on April 25, 2001. The HIA applies to health information in the custody or under the control of custodians primarily in the publicly funded health sector. The Act demonstrates to Albertans and to health providers the commitment to protect the privacy of the individual and the confidentiality of their information.

The Act has been in force for three years. During this time, there have been significant developments which will influence the review of the collection, use, disclosure and protection rules detailed in the HIA.

- Canada's *Personal Information Protection and Electronic Documents Act* (PIPEDA) came into force on January 1, 2004 for health entities in Alberta such as private pharmacies, laboratories and health care providers in private practice;
- The *Personal Information Protection Act* (PIPA) came into effect on January 1, 2004;
- The implementation of Alberta's province-wide Electronic Health Record; and
- The development of the pan-Canadian health information privacy and confidentiality framework.

The HIA requires that a Special Committee of the Legislative Assembly must begin a comprehensive review by April 25, 2004 and submit a report to the Legislative Assembly including the Committee's recommended amendments within one year.

This Committee will focus upon:

- The Act and its supporting policies and administration to determine whether an appropriate balance has been achieved between protection of the individual's privacy and access to health information where appropriate to provide health services and to manage the health system.

- The application of this Act
  a. to departments of the Government of Alberta
  b. to local public bodies as defined in the *Freedom of Information and Protection of Privacy Act*, and
  c. to any other entity that is not a custodian and has information about the health of an individual in its custody and under its control.

- The impact of electronic health records on the HIA rules.

- Whether the recommended amendments to the HIA address the intent to harmonize rules in the pan-Canadian health information privacy and confidentiality framework.

This review does not include:

- Protection of personal information and privacy under the purview of the *Protection of Personal Information Act* (PIPA) except for health information contained in employee health records.

- Access/privacy and confidentiality protection of personal information in the *Freedom of Information and Protection of Privacy Act* (FOIP).

The information management environment resulting from recent technical advancements is significantly different than in 2001 when the Act came into force. For example, the development of the province-wide Electronic Health Record will require a review of the application of the Act, the definition of custodian and the rules on access to one's own health information.

Part 1 – The Purposes, Definitions and Scope

The Purposes

HIA rules reflect seven key purposes as follows:

(a) to establish strong and effective mechanisms to protect the privacy of individuals with respect to their health information and to protect the confidentiality of that information,
(b) to enable health information to be shared and accessed, where appropriate, to provide health services and to manage the health system,
(c) to prescribe rules for the collection, use and disclosure of health information, which are to be carried out in the most limited manner and with the highest degree of anonymity that is possible in the circumstances,
(d) to provide individuals with a right of access to health information about themselves, subject to limited and specific exceptions as set out in this Act,
(e) to provide individuals with a right to request correction or amendment of health information about themselves,
(f) to establish strong and effective remedies for contraventions of this Act, and
(g) to provide for independent reviews of decisions made by custodians under this Act and the resolution of complaints under this Act.

Another purpose that has been suggested is…to establish mechanisms to ensure transparency and accountability for the collection, use and disclosure of personal health information.

Question?
Are the purposes in the HIA appropriate? If not, please explain why and make suggestions for improvement. Would the inclusion of the additional purposes be acceptable? If not, why not?

The Definitions

In general, the definitions within the Act assist in interpreting the provisions throughout the legislation.

Question?
Are there any definitions that should be modified? If so, kindly provide the rationale for the modification and any suggested wording.

The Scope

The scope of the Act reflects two essential dimensions:

- Who the Act applies to; and
- What type of information is covered under the Act.

The Act applies to "custodians" of health information primarily in the publicly funded health sector.

Custodians include:

- the Minister and department of Alberta Health and Wellness
- Regional Health Authorities
- the Alberta Cancer Board
- the Alberta Mental Health Board
- hospitals and nursing homes not directly operated by the health authorities or boards
- health service providers paid under the Alberta Health Care Insurance Plan (i.e. physicians, chiropractors, dental

surgeons, dental mechanics, opticians, optometrists, podiatrists and osteopaths)
- pharmacists and pharmacies regardless of how they are paid
- boards, agencies, committees and other organizations identified in the regulations.

The Act also extends to "affiliates" of custodians. Affiliates include employees, agents, volunteers and physicians paid by a custodian or having privileges with a custodian.

Alberta Alcohol and Drug Abuse Commission (AADAC) and Persons With Developmental Disabilities (PDD) Boards are specifically excluded from the scope of the Act. Also, the Act does not include an operator as defined in the *Ambulance Services Act*.

The Provincial Steering Committee on the *Health Information Act* in the report of June, 1998 recommended that health information collection, use and disclosure rules should apply to both public and private sectors. This Committee argued that private sector entities that hold health information should be fully covered by the legislation to create a level playing field and ensure that the individual's privacy is protected regardless of whether the custodian is a public or a private sector entity.

The Government did not adopt this recommendation but recognized the importance of further considering the scope of the legislation by mandating the Special Committee of the Legislative Assembly to include a review of the application of the Act to other departments of the Government of Alberta, to local public bodies as defined in the *Freedom of Information and Protection of Privacy Act* and to private sector health entities.

Question?
Should the scope of the Act be expanded to include other departments of the Government of Alberta, local public bodies as defined in the *Freedom of Information and Protection of Privacy Act*, and to any other entity that is not a custodian and that has health information about the health of an individual in its custody or under its control? If yes, what is the rationale?

The Act intentionally does not include ambulance operators. Health information collected, used or disclosed by ambulance attendants is subject to the *Ambulance Services Act* and the Confidentiality Regulation (Alta. Reg. 38/99) made under that Act. Demographic and other pre-hospital information collected by ambulance attendants continues to be governed by this legislation. However, if that information is provided to a hospital upon arrival, it becomes part of the patient's health care records and is subject to the *Health Information Act*.

Government policy at the time the *Health Information Act* was drafted was that all ambulance operations should continue to be subject to the Confidentiality Regulation of the *Ambulance Services Act*. This was based on the rationale that considerable work had gone into the review of this regulation (as part of the regulatory reform initiative) and that ambulance operators had been consulted and were used to working with the ambulance confidentiality rules. The intent was to harmonize the ambulance confidentiality rules with the health information rules as appropriate.

After the HIA was proclaimed, there was some question in regard to the application of the HIA to ambulance services owned/operated by a custodian or in a contractual relationship with a custodian

organization. It was determined that these ambulance operators were in fact bound by the HIA based on their relationship as an affiliate of a custodian. (This includes STARS Air Ambulance that is operated by Alberta Health and Wellness.)

In the spring of this year, a decision was made to transfer ground ambulance governance and funding responsibility to health regions from municipalities in 2005-2006.

When authority for ground ambulance is transferred to the health regions, ground ambulance operators will be affiliates of the region and the service will therefore be bound by the HIA.

Question?
Should operators as defined in the *Ambulance Services Act* be included in the scope of the Act? If yes, what is the rationale?

Alberta, along with other Canadian jurisdictions is developing a provincial Electronic Health Record (EHR). An EHR is a collection of the individual's health information gathered from different health professionals over time. Examples of this type of information may include lab test results, prescriptions, or allergies.

For the EHR to be effective, it has been suggested that the application of the Act needs to be extended beyond the publicly funded health sector to include all health entities engaged in providing care and treatment regardless of their source of funding. The goal of the provincial EHR is to provide better information, for better quality of care.

Question?
Should the scope of the Act be changed given the implementation of the Electronic Health Record? If so, how? Please provide the rationale for the suggested changes.

The Act applies to health information about an individual and includes three types of information: diagnostic, treatment and care information, registration information and health service provider information.

Including health services provider information under the HIA was intended to ensure that there is transparency regarding the use and disclosure of this information under the Act.

The Act provides specific and limited protection for health service provider information. Rules in the Act are primarily intended to reflect cases when health service provider information is linked with the individual's health information. Indeed, information about health service providers may be linked with individual's health information. Other than disclosure to health professional bodies and permitted disclosure of basic "business card" type information, the Act only permits disclosure if it is authorized or required by an enactment of Alberta or Canada.

The policy intent was that custodians should request the provider's consent for disclosing identifiable health service provider information to non-custodians for use by non-custodians for a commercial purpose.

Question?
Should health service provider information be included within the scope of the Act? If not, kindly provide the rationale.

The *Personal Information Protection Act* currently applies to health information as defined in the HIA that is personal employee

information. This would include health information collected by an employer when needed to establish, manage or terminate an employment relationship. For example, this would include a physician's note excusing or related to a return to work, or medical information collected by an employer to comply with Occupational Health and Safety legislation.

Question?
Should personal health information contained in employee health file be part of the scope of the *Health Information Act*? If yes, what is the rationale for doing so; if not, why not?

The Workers' Compensation Board (WCB) was excluded from the HIA because the Act is intended to apply primary to the publicly funded health sector. WCB is funded by employers and reports to the Minister of Human Resources and Employment. It is regulated by the *Workers' Compensation Act* and the *Freedom of Information and Protection of Privacy Act*.

WCB is an independent organization that manages the workers' compensation insurance business. It is an employer-funded organization providing cost effective disability and liability insurance for more than 100,000 employers and over one million workers in Alberta. WCB covers the cost of health care and other costs associated with a work related injury or illness. In providing heath care services to injured workers, WCB works in partnership with physiotherapists, chiropractors, general practitioners, specialists, surgeons and other health care providers.

It has been suggested that health services as defined in the HIA provided and funded by the WCB would benefit from being included in the scope of the HIA, particularly in relation to the use and disclosure of information FOR care and treatment purposes.

Question?
Should the scope of the HIA be extended to include WCB? If yes, kindly provide your rationale?

Alberta Blue Cross Corporation (ABC) provides supplementary health and dental benefit programs to meet the health needs of Albertans. As a third party insurer, the ABC is not publicly funded. Blue Cross pays health services providers for the services they provide to Blue Cross insurance plan members.

Alberta Health and Wellness contracts with ABC to offer the following supplementary health plans – non-group coverage, coverage for seniors (and for recipients of the Alberta Widows' Pension and their dependants) and palliative care drug coverage. Based on the contractual relationship, ABC is an affiliate of the department and the legislation applies to those records created on behalf of the department.

The health information held by ABC for other health insurance plans it administers is not subject to the act. Health information associated with privately funded health insurance plans (e.g. employer sponsored health insurance plans) are regulated according to the agreement between ABC and the plan's sponsor. Health information associated with health insurance plans funded by other Ministers (e.g. health insurance for AISH recipients that are funded by the Minister of Human Resources and Employment) are subject to FOIP.

ABC, then, is subject to the Act, but only for the health information it has for the plans it administers on behalf of the Minister of Health and Wellness.

Question?
Should ABC be subject to the HIA for all health information as defined by the HIA in its custody or under its control? If yes, what is your rationale? If not, why not?

The scope of the Act includes recorded health information i.e. information that is documented, recorded or stored in any form, on any storage medium and by any means. Except for the requirement that a custodian who collects, uses or discloses non-recorded information may only do so for the purpose for which the information was provided to the custodian, the Act does not apply to information that has come to one's attention, but has not been recorded/documented in any way. Broadening the scope of application to include non-recorded health information may strengthen the private rights of the individual but such an inclusion also creates significant challenges and potential administrative burden on providers. For example, it would be very difficult to extend a right of access to the individual's own information, if it is not recorded or documented in any way. It is also noted that confidentiality of non-recorded health information is protected by professional practice guidelines.

Question?
Should the definition of health information be changed to include non-recorded information? If yes, please provide the rationale. If not, why not?

Part 2 – Individual's Right to Access Individual's Health Information

The Act details the individual's right to access any record containing health information about the individual that is in the custody or under the control of a custodian. The right to access health information is subject to limited and specific exceptions as set out in the Act.

The Act also provides individuals with a right to request correction or amendment of health information about themselves and details associated time-lines. The *Health Information Act* Regulations sets out the maximum amount of fees that can be charged to applicants. These fees are considered reasonable to provide individuals with the right to access their own information.

It has been suggested that the individual's right to access their own information within the EHR will require particular consideration.

Question?
Is the process for obtaining access to records appropriate? If not, please explain and provide any suggestions for improvement.

Question?
Are the exceptions to the individual's right to access their own information (both mandatory and discretionary) appropriate? If not, please explain and provide suggestions for improvement.

Question?
Is the amount of fees set out in the *Health Information Act* Regulation appropriate? If not, please explain and provide suggestions for improvement.

Question?
How should the HIA be amended to address the concept of custody or control of a custodian within the EHR?

Part 3 – Collection of Health Information

The *Health Information Act* protects the individual's privacy by limiting the collection of individually identifying health information. The Act requires that information may only be collected if it is expressly authorized by an enactment of Alberta or Canada or that the information directly relates to and is necessary to enable the custodian to carry out an authorized purpose under the Act. Further, the Act states that there is a duty to collect the information directly from the individual except in specific circumstances that are outlined in the Act. These circumstances are:

- the individual authorizes collection from someone else;
- when the individual has had a substitute decision maker appointed;
- where the custodian believes, on reasonable grounds, that collection from the individual who is the subject of the information would prejudice: the interests of the individual, the purposes of collection, the safety of any other individual, or would result in the collection of inaccurate information;
- where collection from the individual who is the subject of the information is not reasonably practicable;
- where collection is for any of the following purposes:
  1. assembling a family or genetic history where the information collected is to be used in the context of providing a health service to the individual from whom the information is being collected;
  2. determining the eligibility of an individual to participate in a program of or to receive a benefit, product or health service from a custodian and the information is collected in the course of processing an application made by or for the individual who is the subject of the information;
  3. verifying the eligibility of an individual who is participating in a program of or receiving a benefit, product or health service from a custodian to participate in the program or to receive the benefit, product or service; and
  4. informing the Public Trustee or the Public Guardian about clients or potential clients.

There is also a duty on the custodian to take reasonable steps to inform the individual of the purpose and legal authority for the collection and to provide contact information for an affiliate of the custodian who can answer questions on the collection.

Only custodians and the persons authorized in the Health Information Regulation have the right to require an individual to provide the individual's personal health number.

Question?
Is the duty to collect health information directly from the individual except as authorized appropriate? Or are there other legitimate circumstances for indirect collection? If so, please explain.

Question?
Should custodians be permitted to collect information about the individual's family health history without the consent of the family members where necessary to provide health care to the individual? Or should privacy protection of the individual not allow this collection?

Question?
Is the requirement to inform individuals about collection practices effective or does it create any operational difficulties? Please explain.

Part 4 – Use of Health Information

The custodians identified in the Act are primarily part of the publicly funded health system. They all have certain responsibilities in the health system, they are funded to fulfill those responsibilities, and they are accountable for the outcomes they achieve.

Generally, all custodians are mandated to:

- provide health services;
- determine an individual's eligibility to obtain health services;
- investigate, review or inspect the services provided by health service providers;
- conduct research into better health practices, services or management;
- provide health service provider education;
- carry out the specific purposes identified in other legislation such as the *Hospitals Act*, the *Public Health Act*, the *Cancer Programs Act* and the *Regional Health Authorities Act*; and
- manage internal operations such as planning and allocating resources, quality improvement, evaluation, obtaining payment for services provided and so on.

In addition, some custodians (i.e. the Minister and department of Alberta Health and Wellness, Regional Health Authorities, and the Alberta Cancer Board) have broader regional or provincial responsibilities. In addition to the above list, these custodians are also mandated to:

- plan and allocate resources on a regional or provincial basis;
- manage the health system on a regional or provincial basis;
- conduct public health surveillance to determine and improve the health of the regional or provincial population; and
- develop health policies and programs on a regional or provincial basis.

At the heart of the Act is a firm understanding that custodians require information to fulfill their mandates. Without information, they are unable to assess the outcomes of their actions, provide quality health services, or meet other expectations and responsibilities. The concept of "controlled sharing" built into the Act means that custodians are permitted to obtain and use the amount and type of health information that is truly necessary for them to perform their mandate. This does not mean widespread uncontrolled sharing of an individual's health information. The "necessity" test is significant. Custodians under the HIA, are to be held accountable for their actions under the Act and need to demonstrate their need for the information they collect and use.

If the scope of the HIA was expanded to include other Government departments, local public bodies and private sector health entities, a careful examination of the purposes authorized under the Act would be required to ensure that an appropriate set of responsibilities is established for those outside the publicly funded health sector.

Most of the rules in the Act apply to custodian-to-custodian interactions and activities within a controlled arena.

Question?
Are the purposes as currently listed in the Act appropriate for existing custodians? If not, how could these be improved?

Question?
If you recommended an expansion of scope of the Act to include other entities, what purposes/set of responsibilities would you change to reflect the mandates of additional custodians?

Question?
Is it appropriate to use identifying health information without consent for the authorized purposes stated in the Act?

Question?
Overall, should the listing of authorized uses be expanded, restricted or modified in any way?

Part 5 – Disclosure of Health Information

Consent for disclosure of identifying health information is an important consideration for custodians. The Act authorizes custodians to disclose health information with the consent of the individual. The HIA states that consent must stipulate:

- who is to receive the information and why;
- the effective dates of the consent;
- specifies about what information is to be disclosed;
- an indication that the individual has been made aware of the reasons why the information is needed;
- the implications to the individual of consenting or refusing to consent; and
- that it must be provided in writing or electronically.

The Act permits custodians to disclose diagnostic, treatment and care information without consent (subject to overriding principles) in specific circumstances. These are discretionary disclosures. Some examples of the discretionary disclosure are:

- to another custodian for authorized purposes listed in the Act;
- to family members or to another person with whom the individual is believed to have a close personal relationship, if the information is given in general terms and concerns the presence, location, condition, diagnosis and prognosis of the individual and is not contrary to the express request of the individual;
- to a committee for carrying out quality assurance;
- to any person to avert or minimize an imminent danger to the health or safety of any person; and
- and if the disclosure is authorized or required by an enactment of Alberta or Canada.

Question?
Are the elements of consent appropriate? Or should consent be allowed to be provided verbally to the custodian? If so, what are the implications?

Question?
Are the discretionary disclosures without consent (subject to overriding principles) as listed in the Act reasonable and appropriate? Should these permitted disclosures be restricted in any way? Please explain.

<u>Disclosure to Police</u>

At the time of introduction and proclamation of the Act, some police services suggested that the discretionary disclosures to police were too restrictive and did not permit police services to obtain health information in a timely manner to protect the public or pursue criminal investigations.

The *Health Information Act* allows custodians to disclose diagnostic, treatment care information in the following circumstances:

- pursuant to subpoenas, warrants or court order;
- to a municipal or provincial police service to investigate an offence involving a life threatening personal injury to the individual unless disclosure is contrary to the express request of the individual; and
- to minimize an imminent danger.

Existing health statutes generally establish an obligation for health professionals to maintain confidentiality of the individual's *health information with respect to all* disclosures. The custodian acts as a gatekeeper and must exercise the appropriate discretion based on all relevant factors in the circumstance and consistent with the Act.

Jurisdictions with health information legislation in effect or introduced have debated the appropriate balance between the privacy rights of the individual seeking care and treatment and the police requirements for access to personal health information. Police services argue that access to personal health information is required to investigate an offence toward ensuring public safety and security and that the requirement for the individual's privacy needs to be balanced with the community expectation for protection and safety.

The challenge is to balance the obligation of health providers to protect the privacy of the individual in the interest of providing care and treatment and the duty of the police to protect and preserve the peace.

The requirement to amend 35(1) (j) to make reference to all police services so as not to exclude First Nations police services has been identified.

Question?
Should the discretionary authority to disclose to police services without the individual's consent, be extended to disclose basic registration information to police services for purpose of providing a warrant, subpoena or court order? If so, why, and under what circumstances? If not, why not?

Triplicate Prescription Program

The Triplicate Prescription Program (TPP) was established in 1986 to monitor the *prescribing and dispensing practices of a* select group of narcotic and controlled drugs with a high potential for drug divergence for illicit purposes. Program participation is mandatory for pharmacists and physicians.

It is the policy position that there is authority under the HIA whereby health information can be disclosed for the purpose of the triplicate prescription program (TPP). The HIA allows custodians to disclose individually identifying diagnostic, treatment and care information and individually identifying registration information without consent if the disclosure is authorized or required by an "enactment" of Alberta or Canada (ss. 35 (1) (p) and 36 (a)). Similarly, the HIA allows custodians to disclose individually identifying health services provider information without consent where allowed by an "enactment" (s.37 (1)(b)).

The College of Physicians and Surgeons of Alberta and the Alberta College of Pharmacists have chosen the mechanism of a By-law and a Resolution, respectively, for TPP disclosures. By-laws and resolutions are both explicitly included in the definition of a "regulation" in the Interpretation Act.

Assuming that the College of Physicians and Surgeons of Alberta and the Alberta College of Pharmacists have the authority to pass such a By-law or Resolution are enactments in accordance with the HIA.

To ensure that there is clear legal authority for TPP disclosures, it has been recommended that the HIA should include a specific provision which allows a custodian to disclose health information without

consent for the purpose of the triplicate prescription program.

Question?
If you disagree with the proposed amendment to specifically reference the triplicate prescription program, please explain your rationale.

Disclosure to Third Party Carriers for Purpose of Payment

The HIA as drafted currently requires the custodian to obtain the consent of the individual to disclose their diagnostic, treatment and care information to third party carriers for purpose of payment. In follow-up to analysis conducted by RxA, and the Canadian Life and Health Insurance Association Inc., in August 2002 the Minister of Health and Wellness advised RxA that Alberta Health and Wellness intends to consider an amendment at the time of the three year review of the *Health Information Act* to provide custodians with the discretionary authority to disclose diagnostic, treatment and care information to third party carriers for purpose of payment without consent. The perspective, in this instance is that the balance appropriately lies on the side of enabling disclosure for this purpose as compared to the protection of the individual's privacy. In other words, the privacy gains for the individual can be considered minimal compared to the administrative burden on the custodian to obtain the individual's consent for this purpose.

Protection and Disclosure of Genetic Information

Genetic information about an individual is generally viewed as information obtained from DNA, gene product analysis of family histories, used to predict susceptibility to illness, disease, impairment or other mental or physical health disorders.

A recent review of the existing domestic and international legal framework, pertaining to privacy and confidentiality of genetic information concluded that existing laws do not extend unique privacy and confidentiality rules for the protection of genetic information. Clearly the technological implications of genetic testing and resulting uses is evolving and necessitates further analysis of what, if any, unique attributes of genetic information require different rules for privacy and confidentiality or different application of the same rules that apply to personal health information.

Genetic information is generally seen in the same light as health information but more fundamentally personal given the potential of allowing discrimination based on genetic characteristics.

Further, the special characteristics of information may reveal information about an individual's future health status and that of family members.

Question?
Should the HIA be amended to include stronger provisions to protect the confidentiality of genetic information? If so, what provisions in the HIA would you suggest?

Consent for Care and Treatment

Under the HIA, a custodian may collect, use and disclose individually identifying diagnostic treatment and care information without the consent of the individual who is subject of the information for care and treatment subject to overriding principles and provisions that restrict the flow of information. The individual does not have the ability to consent or to withdraw consent for care and treatment. However, the Act places a duty on the custodian to consider

the express wishes of the individual in deciding how much information to disclose alone with other factors the custodian considers relevant.

When the HIA was being drafted, there was a conscious decision to codify existing practices within the health sector. Therefore the legislation was drafted to reflect the practice within the health sector. Based on that practice, the legislation authorizes the disclosure of individually identifiable health information between custodians for the provision of health services/care and treatment without consent.

As of January 1, 2004 the Federal *Personal Information Protection and Electronic Documents Act* (PIPEDA) became applicable throughout Canada to all private sector organizations that collect, use or disclose personal health information in the course of commercial activities unless the federal government exempts a province from the application of PIPEDA on the basis that the province has enacted legislation substantially similar to the federal Act. In the health sector, this would include entities such as private pharmacies, laboratories and health care providers in private practice.

Therefore, PIPEDA applies to custodians under the *Health Information Act* such as pharmacies, pharmacists and physician in private practice. Doctor's offices and the offices of other health service providers such as dentists and chiropractors are considered to be engaged in commercial activities. Personal information that is collected, used or disclosed in the course of business by these health service providers is captured by PIPEDA. However, the core business of hospitals puts them outside the scope of PIPEDA.

The Industry Canada interpretation of the PIPEDA consent requirements states that implied, informed consent is appropriate within the circle of care.

PIPEDA requires that consent be based on knowledge. Knowledge means knowing why the information is being collected and how it will be used and disclosed. In a health care setting, a patient reasonably expects that certain uses or disclosures will be required to the provision of care and treatment. For example, the patient reasonably expects that disclosures of his or her personal health information will be made from a general practitioner to a specialist or from a general practitioner or specialists to a laboratory, or – in discussing a prescription, from a physician to a pharmacist. In these situations, implied consent, based on a general understanding of how personal information will be used and disclosed, is acceptable. Industry Canada has advised that health care providers can ensure that patients understand this by providing information on the forms people typically fill out when providing a medical history, and through use of notices, posters and brochures.

According to Industry Canada, the circle of care includes the individuals and activities related to the care and treatment of a patient. Thus, the circle of care covers the health care providers who deliver care and services for the primary therapeutic benefit of the patient and related activities such as laboratory work and professional or case consultation with other health care providers.

Under the HIA, subject to overriding principles such as the need to know, the least amount, highest level of anonymity and other checks and balances to protect privacy and confidentiality, consent is not required

from the individual for the disclosure of health information for the provision of health services to the individual.

Given the PIPEDA and the HIA consent requirements, the key additional requirement is to inform patients of their privacy rights and to provide patients with an opportunity to know what health information is being collected, for what purpose and how the information will be used, disclosed and protected.

For the HIA to be considered substantially similar to PIPEDA, the existing consent requirement may need to be amended to reference informed knowledgeable implied consent model.

In general terms, this consent model could mean:

i)that the individual (based on posters, brochures, etc.) is knowledgeable about the collection, use and disclosure of personal health information;

ii)given that the individual is knowledgeable, the custodian may imply that the individual has consented to the use and disclosure of their personal health information for care and treatment; and

iii)the individual may, based on the knowledge (through posters, brochures etc.) take the initiative to notify the provider that they withhold their consent for use or disclosure of their health information. The individual may choose to withdraw or withhold their consent at any time.

Question?
Is an informed/knowledgeable implied consent model for care and treatment appropriate for Alberta's health system? If not, why not? What would be the operational and service delivery implications of an informed/knowledgeable implied consent model for care and treatment? Please explain.

Research Disclosure

Alberta's health research and the role researchers play a significant role in the provision of quality health services to Albertans. Extensive work on a national and provincial basis has occurred toward protecting the individual's privacy on the conduct of research and ensuring the scientific benefits of research.
The research rules in the HIA respect provisions in the *Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans*. Alberta's research community was involved in working on the research provisions and in the listing of the designated ethics committees.

Question?
Are the research provisions in the Act reasonable, effective and operationally effective? If not, why not? Please provide your suggestions for improvement.

Part 6 – Duties and Powers of Custodians Relating to Health Information

Based on focus group results, Albertans generally appear to have confidence in their health services provider who has custody or control of their personal health information to collect, use or disclose only the information that is appropriate and necessary. Recognizing the trust placed on health service providers by individuals, Part 6 of the HIA includes clear and stringent duties and obligations on the custodian to protect the confidentiality of the individual's personal heath information. This section of the Act requires custodians to collect, use and disclose health information with the highest degree of anonymity possible, and in a limited manner.

Physical, Technical and Security Safeguards

The Act places a duty on the custodian to take reasonable steps to maintain administrative, technical and physical safeguards to protect the confidentiality of health information including health information that is stored or used in a jurisdiction outside Alberta or disclosed by a custodian to a person in a jurisdiction outside Alberta. The Act further requires that appropriate measures be in place for security including risks associated with electronic health records.

Privacy Impact Assessments

Privacy impact assessments are a tool to allow custodians to review their authority for various actions, to compare options and to fully consider the implications of proposed actions on the privacy of the individuals they serve. The HIA requires custodians to complete a privacy impact assessment when:

- a custodian plans to develop or implement a new administrative practice or a new information system;
- a custodian plans to perform data matching with another custodian or with a non-custodian (data matching refers to the creation of individual identifying health information by combining individually identifying or non-identifying health information or other information from two or more electronic databases, without the consent of the individuals who are the subjects of the information); and
- the Minister or the department of Alberta Health and Wellness plans to request other custodians to provide individually identifying health information.

In each instance, the privacy impact assessment must be prepared and forwarded to the Information and Privacy Commissioner for review and comment before the custodian implements their plans.

Information Manager

Under the HIA, an information manager means a person or body that processes, stores, retrieves or disposes of health information; that transforms individually identifying health information to create non-identifying health information and provides information management or information technology services. The Act includes several provisions describing the requirements for entering into an agreement. Given the implementation of the EHR, it has been suggested that there is a need to clarify the use of information manager agreements between custodian organizations in support of the provincial EHR as compared to

information manager agreements used by custodian organizations to deal with outsourcing of technical functions. The Act also clearly states that the custodian continues to be responsible for compliance with the Act and Regulation.

Data Matching

Data matching is a process by which information from two electronic databases is combined to form new identifying health information. From a privacy perspective this is of concern to individuals as in depth individual profiles may be developed through this process. If someone has access to many electronic databases, they can "mine" the data and learn many personal and private aspects of an individual.

Under the Act, custodians are required to justify their need to perform data matching and assess the potential privacy impact on the individuals, who are the subjects of the information to be matched, to the Commissioner. Non-custodians may not take steps to re-identify an individual from non-identifying health information i.e. data match unless a privacy impact assessment on the data matching by custodian and a non-custodian is submitted to the Information and Privacy Commissioner by the custodian.

Custodians are further restricted in that they may not collect health information for data matching, use health information that results from data matching or disclose information for data matching if the collection, use and disclosure is not otherwise authorized under the Act.

Under the Act, the Commissioner may give any person an order to stop data matching and order the identifiable health information that was created to be destroyed.

Question?
Are the duties and obligations on the custodian appropriate and reasonable? If not, kindly provide your rationale and include any suggestions for improvement.

Part 7 – Commissioner

One of the purposes of the *Health Information Act* is to provide for independent reviews of decisions made by custodians under the Act and for the resolution of complaints. This part of the Act describes the right of the individual to ask the Commissioner to review any decision, act or failure to act of the custodian in relation to requests of access, correction or amendment; and to ask the Commissioner to review any collection, use or disclosure believed to be in contravention of the Act.

In brief, this part of the Act provides the provisions ensuring clear and explicit authority for effective oversight and redress.

Question?
Do you have any suggested changes to this part of the Act? If so, kindly identify and explain the rationale for the change(s).

Part 8 – General Provisions

This part of the Act describes the exercise of rights by other persons i.e. the right of substitute decision makers to act on behalf of an individual. The following provisions were placed in the Act to ensure that the rights or powers conferred on an individual in the Act can be exercised by others under specific circumstances:

- guardians may act on behalf of persons under the age of 18 that do not understand the nature/consequences of a decision;
- guardians/trustees appointed for an individual under the *Dependent Adults Act* may act on behalf of the individual;
- agents designated for an individual under a personal directive under the *Personal Directives Act* may act on behalf of the individual;
- persons granted power of attorney by the individual may act on behalf of the individual;
- "nearest relatives" for formal patients under the *Mental Health Act* may act on behalf of the formal patient; and
- any person with written authorization from the individual may act on behalf of the individual.

Question?
Is the list of substitute decision makers appropriate? If not, please explain and provide any suggestions for improvement.

This Part of the Act also includes provisions for offenses and penalties and states that person who is guilty of an offense is liable to a fine of not more than $50,000. The HIA sends out a strong message that any action that contravenes the rules in the Act is unacceptable. It also recognizes that custodians should not be held liable in cases where they took reasonable steps to ensure compliance.

In addition, it is an offense for a custodian to take adverse action against an affiliate because the affiliate, acting in good faith, disclosed health information to the Commissioner or properly disclosed information in accordance with the Act. A custodian could be fined up to $10,000 for this offense.

The *Health Information Act* contains the following offenses, which could impact all Albertans:

No person shall knowingly:

- collect, use, disclose or create health information in contravention of the Act;
- make a false statement, to, or mislead or attempt to mislead, the Commissioner or another person performing the duties, powers or functions of the Commissioner or other person under the Act;
- obstruct the Commissioner or another person in the performance of duties, powers or functions of the Commissioner or other person under the Act;
- fail to comply with an order made by the Commissioner (the Commissioner can order any person to stop collecting, using, disclosing or creating health information in contravention of the Act or require them to destroy health information collected or created in contravention of the Act);

- use individually identifying health information to market any service for a commercial purpose or to solicit money unless the information obtains consent from the subject of the information; and
- perform data matching with non-identifiable health information without first notifying the Commissioner.

The HIA also makes it an offense for researchers or information managers to breach the terms and conditions of agreements entered into with custodians.

As part of the implementation of the Act, the Office of the Information and Privacy Commissioner and Alberta Health and Wellness took an approach of education and training of custodians.

Question?
Are these offenses and penalties appropriate? If not, please explain why not and provide any suggestions for improvement.

Health Information Regulation

The Health Information Regulation includes the list of committees designated as research ethics committees, as well as the list of panels, committees, boards and individuals designated as custodians. Details on the definitions of registration information is included. Rules for ensuring that administrative, technical and security safeguards are in place are also included.

Questions?
Do you have any suggestions for improvement on the rules contained within the Health Information Regulation? If so, kindly explain.

Conclusion

The purpose of this Consultation Guide is to assist in focusing the review of the *Health Information Act* (the HIA) and to ensure that the HIA continues to establish strong and effective mechanisms to protect the privacy of the individual and confidentiality of the individual's health information and to enable health information to be shared as appropriate to improve care and to manage the health system.

Your submission may be sent by mail, facsimile or e-mail. If sending by mail, **please provide 10 copies of your submission**. If sending by e-mail, **please include your mailing address to receive a copy of the Committee's reports**. Where possible, submissions should be signed. Anonymous submissions will not be considered. The closing date for submissions is Friday, August 6th, 2004.

Please send your comments to:

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Please note that submissions will be publicly available in the Legislature Library. Do not include any personal, health or confidential business information that you do not want to be made available to the public.

The Select Special *Health Information Act* Review Committee will consider your input in the preparation of its recommendations. The Committee's report will be provided to the Legislative Assembly and will include a list of respondents.

The *Health Information Act* can be downloaded from the Review Committee website at www.hiareview.assembly.ab.ca If you wish to cite sections of the HiA, please ensure that you cite current section numbers.